Emily Schaller

CYSTIC FIBROSIS

"My future is the brightest it has ever been, and I am beyond excited to see where we are heading."

I was born in 1982 to a very athletic mom, a dad with a mustache, and two older brothers with bowl cuts. The only thing that made me different from them (besides being a short girl without a mustache and bowl cut) was that I was born with cystic fibrosis. My diagnosis came after 18 months of struggles to gain weight and a constant series of runny nose and ear infections. My CF diagnosis in 1983 was grim, but my parents made a decision to not let CF stop me from living.

During the first decade of my life, I was very active and healthy. The only medications I took were vitamins and digestive enzymes. My parents performed my chest physical therapy to help loosen up any mucus in my lungs. As I got older, more medications were developed, and patients were living longer. In my teens, however, I started to develop more lung infections and lose lung function, even though I was on all of the possible CF medications.

In 2007, I decided that there was more that I could do to get my life back. I changed my diet to a whole-foods-based vegetarian diet and started to run and cycle. It took four months to be able to run two miles, but once I could, I kept running. My pulmonary function went up and my hospital stays went down. Since 2007, I have completed 11 half marathons, and I have a goal of participating in one in every state. I also cycle 1,000 miles each year and have completed a half iron distance triathlon. Exercise has definitely given me life.

While I was busy getting healthy, there was some incredible research and development being done for the first drug of its kind being developed to treat cystic fibrosis at its core.

CYSTIC FIBROSIS

Cystic fibrosis (CF) is a life-threatening genetic disease that primarily affects the lungs and digestive system. An estimated 30,000 children and adults in the United States have CF. In people with CF, a defective gene and its protein product cause the body to produce unusually thick, sticky mucus that clogs the lungs and leads to life-threatening lung infections, and/or obstructs the pancreas and stops natural enzymes from helping the body break down food and absorb vital nutrients. Symptoms include:

- Very salty-tasting skin
- Persistent coughing, at times with phlegm
- Frequent lung infections
- Wheezing or shortness of breath
- Poor growth and slow weight gain, in spite of a good appetite
- Frequent greasy, bulky stools or difficulty in bowel movements

Source: Cystic Fibrosis Foundation. "About CF." cff.org

Born and raised in "The Motor City," I am very familiar with rock 'n' roll, sports, Motown, and, of course, cars. Everyone knows that Henry Ford's Model T was where it all started. The more I think about it, my newest medication, Kalydeco, is the Model T of cystic fibrosis designer drugs. It is paving the way for more drugs that will help treat the underlying cause of CF.

I was lucky enough to be in the Phase 2 and Phase 3 clinical trials for Kalydeco. While I know I was on placebo for the Phase 2 trial, it was four days into the Phase 3 trial that I realized that I was on the real thing. Almost instantly I noticed that I could take a full, deep breath without coughing, or run 10 miles and still be full of energy. I feel better today than any time in my life. Soon enough, future generations may be using only a pill or two that is designed just for their gene mutation to control their CF. My future is the brightest it has ever been, and I am beyond excited to see where we are heading.

Emily Schaller was a patient speaker at the ATS 2014 International Conference in San Diego.